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Integrating, advocating and augmenting palliative care in Malaysia: a qualitative examination of the barriers faced and negotiated by Malaysian palliative care non-governmental organisations

| Charlene Lau¹, Martyn Pickersgill²

Background Since its introduction in 1991, Malaysian palliative care has made significant progress, with an estimated 26 non-governmental organisations (NGOs) and 68 government hospitals providing palliative care facilities and services nationwide. Distinct models between these sectors create unique challenges for each sector in progressing palliative care, requiring different strategies to address these.

Methods Drawing on existing literature available on palliative care in Malaysia and interviews from 10 management and healthcare staff of Malaysian palliative care NGOs, this article casts new light on the field. Specifically, the paper explores the various health-related and policy-related challenges NGOs have identified in progressing palliative care in the country, as well as the current and future strategies they employ to address these.

Results Despite immense progress in Malaysian palliative care, existing services cannot meet the current and projected demand. The interviews identify numerous barriers hindering Malaysian palliative care, including financial matters, perception issues, logistical concerns and challenging government policies.

Conclusion Increased advocacy, establishment of specialised palliative care education, and greater co-operation between different sectors are strongly recommended to help develop palliative care in Malaysia.

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Prolonged lifespans for populations worldwide has created a shift towards non-communicable diseases (NCDs) as prevailing causes of mortality. This has increasingly affected developing countries, who are faced with the challenges of managing an aging population as chronic and terminal conditions become more prevalent (1, 2). Palliative care has gained recognition in many countries as a means of providing comfort to those diagnosed with life-limiting conditions.

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In Malaysia, palliative care has made significant strides since its introduction in 1991. Today, approximately 26 non-governmental organizations (NGOs) and 68 government hospitals provide palliative care services nationwide (3-5). However, this is insufficient to support the demand for its services: Malaysia currently has a population of 32 million citizens, with an estimated 56,000 patients annually requiring palliative care (3, 6). Demand is projected to further rise with Malaysia's population growth and aging population (3).

NGOs play a key role in the provision of palliative care in Malaysia. Whilst government-linked palliative care facilities receive government funding, NGOs are run voluntarily, funded by charitable donations and fundraising events (3, 4, 7). Contrasting with the in-patient focus of government palliative care, NGOs largely focus on nurse-led community services which provide care and support to patients and their families in their homes and volunteer-run day care programmes (3-5, 7-9). Many NGOs also provide loans of essential equipment to patients (4). Despite distinctions between NGO and the government palliative care services, they operate symbiotically. Specifically, many NGOs rely on government healthcare for essential prescriptions, and to provide in-patient facilities, whilst government healthcare benefits from the home care service, which helps alleviate overcrowding in hospitals (4, 5, 7).

This study employs qualitative research methods to examine NGOs' involvement in Malaysian palliative care. It focuses in particular on NGOs' perceptions of the various health- and policy-related challenges they have identified in progressing Malaysian palliative care. The paper also highlights some of the current and future strategies NGOs employ to address these.

There is limited literature available on Malaysian palliative care. Several sources, including Hamzah (2010) and Wright et al. (2008), situate Malaysia's palliative care internationally based on the development groups categorized by The Global Atlas of Palliative Care at the End of Life (2, 4, 10). More recent papers also mention Malaysia's 38th ranking in the Economist Intelligence Unit 2015 Quality of Death Index which places it ahead of many of its neighbours – Thailand (44th), Indonesia (53rd), and the Philippines (78th) (1, 3).

As noted above, concerns exist that current service coverage is insufficient to meet the current national palliative care demand, let alone that of the future. This is estimated at 56,000 patients annually, with current NGO capacity estimated to meet only 8.3% of this (3). Furthermore, many palliative care NGOs are situated in urban locations, limiting service coverage to those in rural areas (3, 4, 11). Various other barriers hinder national palliative care provision and advancement, as discussed below.

In particular, financial constraints are a major issue hindering palliative care advancement in Malaysia: whilst the government sector receives funds from the national healthcare budget, this has been minimal due to the prioritisation of other services over palliative care (3-5, 7). NGOs face further financial challenges, having to rely heavily on fundraising efforts that can be difficult and unpredictable (3, 4, 11). This severely limits NGO palliative care provision by restricting the hiring power required to recruit full-time nurses essential to community palliative care and impacts capacity-building as funds are required to cover overhead costs, staff salaries and to source essential healthcare equipment and medications (3-5). It also hinders research efforts, thus preventing NGOs and local policymakers from identifying needs and areas of improvement, and from evaluating the effectiveness of current interventions (3, 12).

Poor awareness of palliative care has been discussed as a major barrier hindering its progress (3-5, 7, 8, 13). Hospis Malaysia found in their 2016 survey of the Malaysian public that 17.2% of their respondents were unaware of the concept of palliative care, but 98.5% support it when further informed (3). Increased awareness of palliative care has been argued to also be of benefit to patients, by providing them with options to manage their end-of-life care (7, 14). Lim (2004) and Hamzah (2010) have also highlighted a lack of understanding and acceptance of palliative care in the wider medical field, which complicates its integration into the national healthcare system.

Further misconceptions arise from the use of morphine in palliative pain management. Although other countries struggle to obtain opiates for palliative care, Malaysia is unique in its readily available supply (1, 2, 4, 5, 7). However, the national morphine usage remains low, with 2015 International Narcotics Control Board statistics estimating Malaysia's opioid consumption of morphine equivalence at 60 mg/person as compared to 281 mg/person in the United Kingdom (UK) (4, 15, 16). Various work has described patients' and clinicians' concerns about morphine addiction, and the lack of education regarding the use of these drugs in local medical schools (2, 4, 5, 7).

Palliative care has also been shown to be omitted from the Malaysian medical and nursing curriculum, with ramifications that include limited understanding and acceptance for palliation in the wider medical field, and a shortage of qualified palliative medicine clinicians (3, 5, 7, 8). These issues have prompted recommendations for the inclusion of specialist palliative care courses in local medical and nursing schools for both adult and paediatric medicine. Such curriculum modifications have been argued as necessary to ensure that the national capacity to provide palliative services can support the projected increase in demand (3, 5, 7, 13).

The current emphasis of Malaysian palliative care is on cancer, with many NGOs specifically focusing on cancer patients, and those accepting patients with other life-limiting conditions reporting over 90% of patient cases with cancer (3, 4). Chong and Abdullah (2017) and Hamzah and Kuan (2011) also note the focus on adult palliation in Malaysia, neglecting the needs of children with life-limiting conditions (8, 17). Although many government and NGO providers accept paediatric patients, they are not sufficiently equipped to do so, due to a lack of paediatric specialists in the field (8, 17). Paediatric palliative care also disproportionately favours cancer patients, which has been estimated to account for only 25% of the national paediatric palliative care demand, rendering such services inaccessible to a large proportion of children who require palliation (3, 8).

METHODS

This study aims to elucidate understandings of the broader policy, economic and social contexts of Malaysian NGO palliative care, and particularly the challenges faced in advancing this field and practice. As discussed above, there is scant literature available on Malaysian palliative care, some of which may be outdated. Accordingly, a systematic review to address questions of how various health- and policy-related challenges NGOs have identified in progressing palliative care in Malaysia is unfeasible. Primary research is thus required, and here we employ qualitative methods to explore personal experiences and perspectives on this subject (18, 19). Specifically, 10 semi-structured interviews were conducted with members of Malaysian palliative care NGOs.

Sampling and recruitment

To collect diverse and comprehensive views on the topic, purposive sampling was used, focusing on two specific groups: management and healthcare staff of palliative care NGOs. The sampling process also considered the location of the NGOs from where participants were recruited. Malaysia is split into two major parts, with unique differences that could be important to the research context, including differing demographics and the significantly greater rural area in East Malaysia (20). With these considerations, the inclusion and exclusion criteria for the study were: first, management staff or healthcare professionals (doctors or nurses) working with Malaysian palliative care NGOs; second, worked with these NGOs for three years or longer; and, third, fluent in English.

Respondents were recruited through direct contact with palliative care NGOs who had agreed to participate in the study, following initial discussions over email (Table 1). They were provided a consent form and an information leaflet detailing the project aims, the nature of participants' expected involvement, and investigator contact details. Interviews were conducted

Table 1. Details of study respondents

RESPONDENT	STAFF CLASSIFICATION	PALLIATIVE CARE NGO	REGION
1	Management	A	West Malaysia
2	Management	A	West Malaysia
3	Healthcare	A	West Malaysia
4	Management	A	West Malaysia
5	Management	B	East Malaysia
6	Healthcare	B	East Malaysia
7	Management	B	East Malaysia
8	Management	B	East Malaysia
9	Healthcare	C	East Malaysia
10	Management	C	East Malaysia

NGO – non-governmental organization

over three weeks in summer 2017. All respondents were interviewed in their workplace. The interviews, lasting between 35 to 80 minutes, were recorded and transcribed verbatim using NVivo 11 (QSR International, Melbourne, Australia) (21).

Data analysis

Data was analysed thematically and inductively through comparative analysis, with thematic codes developed through repeated close-readings of the transcripts (22, 23). These findings were analysed against the background of the literature review, with documents obtained for this also coded for purposes of comprehension and content summarisation (24).

The coding process employed throughout the data

analysis drew on the principles of grounded theory, to ensure that the findings closely reflected the generated data (22, 23, 25). Codes were stored in NVivo 11, enabling the visualisation of recurrent codes and the retrieval of the relevant data and supporting contexts (21).

Ethical practice

Ethical approvals were obtained from the University of Edinburgh, and the NGO organizations participating in the study. Great emphasis was placed on transparency, documentation of correspondence, and strict adherence to the research protocol. Participant confidentiality was maintained through proper handling of participant-identifiable documents, including the consent forms, transcripts and correspondence, and through careful handling of participants' representation within this article itself, since the small number of institutions within Malaysian NGO palliative care presents anonymization challenges. CL accompanied a nurse on some home visits, in order to better understand the nature of their work. However, no ethnographic notes were taken and those visits served as important context, rather than data, for the study (and hence are not discussed herein). Throughout the research process, careful considerations were made to ensure that the project was sufficiently rigorous in its approach using Green and Thorogood's framework for maximising rigour in qualitative research through clear outlines of the research methodology in the research protocol, and comprehensive audit trails (26).

RESULTS

In this section we present the findings of our study, which we group within five overarching themes that draw together much of the coded data. First, we focus on "Defining and Doing Palliative Care", where we illustrate some of the practices and challenges associated with palliative care more generally in Malaysia. Then, we set out 'The Challenges of Palliative Home Care', which attends specifically to the logistical and other difficulties that must be negotiated by the NGO staff interviewed. Next, we deal with "Integrating with Wider (Public) Healthcare"; in this section, we highlight why such integration is deemed desirable, what some of the associated challenges are, and how they are addressed. After this, we examine the 'Financial Constraints' that palliative care NGOs have to work with, and explore the multiple ramifications of funding limitations for the functioning of the organisations and the kinds of care they provide. Finally, we analyse 'Advocacy and Awareness-Raising', demonstrating some of the concerns our respondents have about the professional and wider public opinion about palliative care NGOs, and how they seek to shift this (in part, to enhance the financial and reputational strength of NGOs, so as to provide high-quality care to more patients).

Defining and doing palliative care

All respondents agreed that palliative care NGOs had genuine intentions to provide care to their patients and in advocating for their cause. In discussing its various meanings and definitions, respondents generally emphasised the holistic nature of palliative care:

“palliative care is whenever their needs, regardless of physical, emotional, spiritual ...psychology, so all this, we need to see them, as a patient, as a whole patient, regardless of what else, what is their sickness” (R6H).

However, some participants rendered problematic the diverse meanings that could be attached to ‘palliative care’ and similar terms. Three respondents specifically quoted the World Health Organization’s definition of palliative care, admitting that this could be too broad at times. Others highlighted its various interpretations; from alleviating suffering as pain and symptom management, through medications, to abstract understandings of providing simple drink, food and companionship. Furthermore, polarising understandings of palliative care exist: for some, it focuses on pain and symptom management, for others, palliative care emphasises life-prolonging treatments. Two respondents felt that life-prolonging treatments were unnecessary in palliative care, since high treatment costs detracted from alleviating pain and symptomatic concerns, potentially increasing patient suffering:

“palliative care itself has evolved into two types - one is pure control, pain and symptoms...you need a few drugs like morphine, and can do the whole thing. But there is another, palliative care which is, you don’t let go of the patient until he dies. You know, so suffering, they use more medicines, more, these, these are patients who are very terminal” (R5M)

Palliative care is, in a range of ways, difficult to deliver, including emotionally. However, the participants described it as a special and important kind of work that they took pride in delivering; as R3H put it, *“there is a beauty in our job”*. The respondents sometimes negatively contrasted the care delivered elsewhere within medicine – where patients might be “put somewhere in the back and nobody bothers with them” (R5M) – in comparison to that delivered by palliative care NGOs. For instance, two of the nurses interviewed described the lack of compassionate care experienced by patients whilst in the hospital setting:

“a lot of the feedback from the patient, they say doctor did not tell them, doctor didn’t explain to them, so they didn’t, they didn’t talk to them, they didn’t communicate with them, they don’t know what is going on” (R3H)

Another point of contention regarding palliative care is its use of painkillers, particularly morphine, for symptom and pain control. Many respondents highlighted resistance to patients taking their prescriptions, despite enduring intense pain:

“a lot of patients and their family, their families especially, are scared of taking opioids because they, they are scared of addiction, you know, the previous history of opioids being from opium, they are scared of addicted, and then, and then, heroin addiction has such a bad name in Malaysia, right, it’s again, it’s opium, so people have that misconception.” (R10M)

Partnerships and support with other sectors are crucial in mitigating some of the challenges faced by palliative care NGOs. For example, respondents described partnerships with other NGOs which have helped alleviate financial constraints, including helping them to *“raise funds or give us some donations”* (R10M) (such as direct monetary assistance or other essential medical equipment). Some welfare-based NGOs were also described as providing financial support to lower-income families to alleviate the costs of medical supplies and treatment. Faith-based NGOs were highlighted as providing support and religious counselling to patients and their families: *“if we need their help, especially the spiritual point of view, we do get in touch with them to see the patients on this”* (R7M). Still, inter-NGO work was not always straightforward, with a lack of standardised care across NGOs making patient transfers difficult, as operational systems and care procedures vary widely between them.

Beyond direct care work, NGOs also engaged in a range of research, education, and advocacy activities (the latter are focussed on below). For instance, respondents mentioned the importance of research to provide evidence-based support for their services, and to ensure that standards and quality of care are not only maintained but improved. Four respondents highlighted their respective NGOs' research endeavours, ranging from community palliative care needs assessments, to updates on the current state of national palliative care. One of the NGOs emphasised the advancement of national palliative care standards through improved education, training, and research. Respondents highlighted the need to improve the practice and image of Malaysian palliative care, which would feedback into increased support from both financial and public acceptance standpoints:

“with better care, you get higher donations, higher patient satisfaction...if you embrace improving standards and quality of care, the money will come- and it has always been proven to be true” (R1M)

During the interviews, respondents highlighted various perceptions that they felt were prevalent within Malaysia and that hindered the advancement and provision of palliative care in the country. They described these as encompassing the medical community, government, patients and their families, and the wider public. R4M described how *“Nobody wants to talk about end-of-life-care”*, and some respondents felt that palliative care NGOs were seen as only for those who *“don't have a chance, a hope”* (R7M). This in turn had implications for income-generation:

“we have had major challenges in fundraising, because palliative care was seen as not useful- why do we need to donate to a service that's dealing with the dying? Let's donate to oncology, to cardiology, to orphanage, to children's, anything - not palliative care.” (R1M)

Societal attitudes and the need for income-generation are important issues for palliative care NGOs in Malaysia, and below we discuss some of the wider effects and implications of financial limitations, as well as how advocacy work was orientated towards shifting public perceptions. First, though, we discuss some of the challenges relating to home care specifically.

The challenges of palliative home care

Many NGOs in Malaysia emphasise community palliative care through home care and day care services. Home care mainly involves nurses travelling to patients' homes to provide care. In contrast to home care, day care had the advantage of allowing patients to receive community support, companionship from volunteers and *“complimentary therapy, like art therapy or even massage”* (R10M). Other services described include loans of medical equipment such as oxygen tanks to alleviate the financial burden of patients in sourcing this essential equipment.

Respondents described home care as entailing the education of patients' families and carers on proper care. They also highlighted the counselling provided for both patients and family members. This was in relation to emotional and spiritual wellbeing, as well as bereavement counselling to support the families of patients. Care also went beyond healthcare *per se*, and (as indicated above) included financial support through sourcing financial aid from various other NGOs or government institutions.

All the healthcare professionals interviewed highlighted the emotional nature of their work. Further difficulties include the long hours and travel demanded by their jobs. They are required to travel to patients' homes, which may sometimes be in remote locations, or require extensive travel due to heavy traffic or poor transport links. The difficulty of their work is further exacerbated by safety concerns; for instance, the medical supply bag that certain nurses carry during their home care visits sometimes contain morphine, making them prime targets for drug addicts.

Safety issues also related to the rural location of some patients. Although all the NGOs in this study were based in urban areas, the service coverage of some included more remote areas with poor transport links:

“it’s also a distance, and sometime the houses are very far in. Sometimes, you might have to walk, might have to walk, and sometimes, of course there is accessibility problem. But there are times that, it is not accessible to roads, so we might have to walk.” (R7M)

Such cases create difficulties in ensuring equitable access to care, since the immense effort and time required was noted as detracting from other patients. Accordingly, some NGOs choose not to provide home care in areas that are difficult to access, which renders palliative care inaccessible to rural patients. This point was corroborated by half of the respondents, who describe this as a significant injustice – but one that they are unable to resolve in their current situation. Contrastingly, urban areas present their own unique logistical concerns: respondents cited heavy traffic as limiting the number of patients that nurses can feasibly visit.

Certain government policies were mentioned as barriers in NGO palliative care provision. For example, nurses are not allowed to prescribe medications, thus limiting their ability as primary caregivers in the home care service to provide the medications required. While some NGOs are able to provide treatment and medications as part of home care, others are unable to do so due to nurses being the key care providers and hence subject to these legal (and financial) constraints, or because licenses are not yet in place. These NGOs have to refer patients to local hospitals for further treatment and prescriptions:

“even if there is a doctor here, we cannot prescribe, because we don’t have that licence yet, because you have to have a licence and you have to have a resident, a doctor and a pharmacist, licence to purchase that” (R7M)

Consequently, palliative care NGOs are forced to rely heavily on government healthcare to ensure a supply of medication for their patients. These matters indicate the importance of (problems with) integrating with wider healthcare, which we attend to next.

Integrating with wider (public) healthcare

Various palliative care NGOs highlighted their role as providers of palliative care education and training. This includes attachment opportunities for medical students and educational visits: *“we always want to continue to educate and make, anytime anybody wants to come for attachment, they’re most welcome” (R8M)*. Training opportunities were also generated through workshops and seminars that draw from both local and international expertise. These focus on skills central to palliative care provision, including patient communication and independent patient care. The organizing of palliative care conferences and *“several workshops a year” (R2M)* often welcomes participation from those outside palliative care, allowing them to gain an increased understanding and appreciation of palliative care. Some respondents also mentioned sending members of their team abroad to share their expertise around palliative care in a low-resource setting. Collectively, these demonstrate that palliative care NGOs seek to integrate with wider healthcare through the vertical and horizontal sharing of expertise.

Interactions with the wider healthcare infrastructure could be challenging, however. Four respondents claimed that *“the government has not been doing enough” (R10M)*; they suggested, for instance, that the government needed to provide coherent policies matching the pledges made on international platforms to advance palliative care. Further, *“a national integrated plan” (R2M)* was required, which should not only entail establishing palliative care units in hospitals nationwide, but ensure that these are well-staffed and equipped to provide palliative care. Half of the respondents expressed the need for the inclusion of palliative care in the national education system, *“not only in medical school, nursing school, but in others” (R6H)*.

Although most palliative care NGOs welcome opportunities to integrate with the national healthcare system, many respondents stated that current practices are hostile to palliative

care and to NGOs delivering this. For example, many hospitals are not equipped with policies to handle palliative care patients, resulting in much confusion during their admission and care. Further, respondents highlighted the lack of standardisation within healthcare systems, not only between government or private hospitals and that of palliative care NGOs. They described a discord in the systems used within the different government hospitals, complicating the movement of information necessary for patient transfers and communication between healthcare professionals. This created a range of issues, including confusion regarding patient prescriptions and patients being denied admission.

The respondents also detailed difficult interactions with hospital clinicians. These included challenges in convincing them to refer patients to palliative care NGOs, with patients often only being referred as a last resort:

"I think, people in public not really knows about what is palliative, they thought that 'Oh, palliative is only, when the times, waiting to die, so that's why most of the doctors, also, they don't refer their patient to us, sometimes when the patient comes, they already are now end-stage'." (R6H)

This scenario was recounted by numerous respondents, especially healthcare staff who mentioned that late referrals posed major issues. These included drastically reducing patients' care options, and unnecessarily prolonging their suffering (since they would not be receiving pain-alleviating treatments outside of palliative care). Others highlighted that late referrals left patients' families less time to prepare for their passing. Since late referrals result in palliative care NGOs only becoming involved in what is essentially witnessing the dying process, this was judged to further perpetuate negative stereotypes:

"even doctors are a little bit resistant to, to palliative medicine, because palliative medicine is a sort of failure. Doctors, we are trained to cure, but when we don't cure, it's sort of, like, a failure. So, some doctors, don't pass their patients to the palliative care until they are, literally a few days left." (R10M)

Other perception issues highlighted relate to their status as an NGO charity. Six respondents mentioned this as a challenge in their endeavours to establish palliative care as a *bona fide* medical field. Participants felt that palliative care NGOs were viewed as cash-strapped and (hence) incapable of providing quality care. Furthermore, they expressed that their organisations were perceived as being an option only for the poor, resulting in many patients and families avoiding them out of fear of being judged as 'too poor' or not 'caring enough' about the patient to spend on hospital-based care.

Some respondents commented on the commitment of the government towards palliative care nationally, mostly commending them for acknowledging palliative care, making efforts to establish palliative care units in government hospitals, and for participating in international pledges on palliative care. However, seven respondents expressed concerns that the government was not truly invested in palliative care; they note a lack of solid effort to integrate it into the national healthcare system, or to ensure that palliative care units are adequately staffed. This was judged to create further issues in advancing palliative care nationally, with some respondents describing these units being perceived as places to die, with admitted patients given poor care and neglected in favour of patients in other wards:

"if you don't create the right perception as to what proper palliative care is, that, that's probably your starting point with your patients. If it's seen as a death ward, then nobody wants to go, right?" (R4M)

We can see, then, that a negative feedback loop appears to exist in palliative care with regards to its relationships with an integration into wider healthcare, such that negative impressions and perspectives can enjoin particular medical practices (eg, late referral) which end up reinforcing stereotypes (eg, that palliative care exists only for untreatable patients very close to death). Placements, conference attendance and invitations can be used as a means of moderating and shifting negative assumptions, and can be regarded as part of the wider

advocacy strategy of palliative care NGOs that will be discussed in greater detail later in the paper. Next, we discuss the considerable financial challenges facing the NGOs, which again, advocacy work aims to help address.

Financial constraints

Palliative care NGOs provide their services free-of-charge. Therefore, increasing patient numbers arising from an aging population, expanding city lines, and greater demand for palliative care have resulted in greater organisational and financial pressures. In particular, financial constraints are a major barrier hindering NGO palliative care provision, with funding concerns expressed (to varying degrees) by all respondents in this study. Some more-established institutions acknowledged funding as a relatively minor concern: a good reputation earned through patient satisfaction and years of active service has helped in fundraising endeavours, for instance. Conversely, smaller and less-established organisations highlighted finance as a more crucial issue hindering the extent and quality of their services.

The government sector has been a source of support for some palliative care NGOs. This includes monetary assistance – *“a grant of few thousand every time a minister come to our charity dinner or marathon”* (R10M) – or funds awarded when NGOs *“apply for a grant every year”* (R6H). While palliative care NGOs can receive limited government grants, many respondents noted that these are insufficient to support operating costs. Accordingly, government funding can be relatively unpredictable. So, too, are public and private donations, on which palliative care NGOs are heavily reliant:

“because NGO is not a government funding, okay, it’s totally from public, so we don’t expect public will give donations the same amount every month. Sometimes, we got jackpot, sometimes, we got nothing in month” (R9H)

Funding issues have been compounded by a recent economic downturn, culminating in dual effects of declining donations and increasing costs of operation:

“as economic conditions decline or if economic conditions become more challenged, then we become more income-challenged as well, cause corporations then begin to lower the amount of money, the amount funds they would contribute” (R2M)

Financial constraints often impact NGO staffing. Services primarily rely on healthcare professionals, with management staff to coordinate daily operations and to manage advocacy efforts and fundraising. Many respondents noted that financial constraints restricted the number of individuals they could feasibly hire, thus limiting their active patient capacity and the frequency of their home visits.

All respondents mentioned the key role nurses played in community palliative care. Due to resource limitations, these nurses were required to perform multiple roles during their home care visits – as nurse, doctor, social worker, counsellor and companion. Many respondents mentioned difficulties in sourcing and recruiting individuals who are willing and capable of doing such work:

“this calls for special people, so those in palliative care, I say, special people. They’ve got to have not only the medical knowledge to deal with what they’ve got to deal with, but they’ve got to also have the emotional strength to withstand all the pain that is surrounding them, but also the passion to help those who are in this state to help them to successfully overcome whatever, whatever fears they might have” (R2M)

Besides staff recruitment, staff retention is also a problem; for example, one respondent mentioned that despite the competitive salary their NGO provides, they struggle to retain staff due to the lucrative salary and benefits offered by the private sector or from abroad. Some respondents also mentioned the difficulties in sourcing new volunteers, with the primary issue being the perceived emotional burden associated with palliative care.

Funding was also a key limiting factor in expanding NGOs range of services. For example, none of the organisations included in this study offer in-patient palliative care. Due to the excessive costs involved with maintaining 24-hour care, many respondents cited its unfeasibility. From interviews conducted with the management staff, four noted that their funds were sufficient to maintain their current services, yet these need to be carefully managed to enable sustainable operations. Thus, many NGOs were hesitant to expand not only their suite of services, but also their service coverage.

It is worth noting, however, that the interview narratives did not focus merely on financial limitations, but also included discussions of funds raised through a range of strategic partnerships and altruistic support. For example, some respondents described receiving support from family members or close acquaintances of former patients:

“The ones who can afford it, will donate back. The ones who can’t afford it will be our biggest advocates anyway, so through word of mouth, they will be spreading the word about the work that we do” (R4M)

Successful advocacy efforts were also an important mechanism for leveraging financial support, and it is to these that we now turn.

Advocacy and awareness-raising

Several suggestions were proposed by respondents to improve the state of Malaysian palliative care, but all respondents especially highlighted the importance of advocacy. This included discussing their own role as advocates for palliative care - either through large and small campaigns (e.g. fundraising benefits and leafletting) or service provision. The NGOs’ staff interviewed described aiming to negate various misconceptions and negative perceptions by providing quality services and through personal interactions with patients and their families. For some, advocacy included the need to improve standards of Malaysian palliative care, its integration in the national healthcare system, and the establishment of specialised palliative care education locally. Several respondents detailed their advocacy amongst their colleagues in healthcare institutions, or through interactions with family and friends.

As touched upon above, many respondents cited ignorance and negative attitudes from local government and private healthcare institutions towards palliative care NGOs. The healthcare staff interviewed detailed their efforts to improve awareness and acceptance of palliative care within these sectors, including through inviting hospital staff to participate in home care visits to provide first-hand experience on palliative care:

“the feedback from the doctors that follow me for home visit, really opened their eyes, about the humanities and how to treat the patient, said, not, doesn’t based on the paper, the books only. You have to go and see, then you understand” (R9H)

The “attitude of the community” (R1M) was described as a massive barrier hindering the progression of palliative care nationally, and hence, respondents argued for the need to generate “more public education and awareness” (R10M). As R4M reflected, “unless people know what palliative care is and what the benefits of palliative care is, they’re not going to be able to ask for it”. Relating to this, the respondents noted issues around awareness amongst local clinicians and the wider public regarding the conditions which would benefit from palliative care:

“there is a very little awareness in Malaysia amongst people with regard to palliative care, they don’t understand, they don’t know palliative care, they don’t understand what it is, and they do not realise what services are available for those suffering from life-limiting illnesses- cancer, HIV, motor neurone disease” (R2M)

On local and national scales, the use of “news releases or articles” (R4M) in media campaigns was recounted as one key means to reach a wider audience. Some respondents describe partnerships with media organisations, resulting in increased promotional coverage of palliative care in the media. Other ways include campaigns targeting specific groups, such as the distribution of pamphlets in schools to increase palliative care awareness in the younger gen-

eration. Exhibitions such as “*photography exhibitions*” (R4H) have also been used to engage the public, with “[*a*]*nti-cancer exhibitions*” (R5M) seeking to improve awareness and acceptance of cancer screening and palliative care for those diagnosed.

Fundraisers were also mentioned as an important advocacy tool, since their publicity helps disseminate palliative care messaging to the public. These are also a major strategy employed by palliative care NGOs to address their financial barriers, with some NGOs hosting fundraisers across the year. Several respondents mentioned the importance of generating good publicity for these events – ensuring public interest in both their events and their cause, and to increase ticket sales and the funds these generated. All the respondents described successes from their fundraisers, stating that such events usually yielded capital sufficient to cover basic operational costs.

To summarise, NGOs actively advocate for palliative care in a variety of ways, as a consequence of poor awareness of services, and indeed the need for them, that NGO staff encountered in a range of national and local settings. Advocating for palliative care promoted positive messaging about services, which was understood to enhance political and clinical attention, referrals, patient access, and funding.

DISCUSSION

Contextualising the findings

As we have seen, resource limitations are a key issue faced by palliative care NGOs. Our respondents described minimal government funding, prompting a heavy reliance on funds sourced from donations. They stressed the negative implications of these resource limitations for their service capacity, such as with regards to staffing concerns, as well as for their ability to expand service provision. These findings concur with the wider literature available, which has emphasised the various barriers involved in palliative care provision in low-resource settings on the subject; for example, Hospis Malaysia (2016), Hamzah (2010) and Lim, (2004) (3–5). This literature has detailed a lack of stable funding as hindering current service provision, but also highlights that existing services are insufficient to meet current needs and the progressively increasing demand associated with an aging and expanding population (3, 4). Furthermore, it has been noted that limits to fund hinders research efforts, as available resources would be diverted to providing essential physical services over advocacy and research (3, 12).

During the interviews, discussions regarding service limitations elicited concerns regarding the neglect of inaccessible and rural populations. Respondents highlighted the injustices of inaccessible palliative care to remote populations, but described how resource limitations and logistical concerns prevent them from managing such cases. Local literature has also discussed this issue, noting its pertinence in East Malaysia which has significant rural land mass (11, 20). As many palliative care providers are based in urban areas, the availability of care to rural populations is restricted (3–5, 7, 11).

The struggles of obtaining sufficient resources for services spotlights existing concerns regarding the ethical justification of palliative care in low-middle income countries (LMICs), with quality end-of-life care seen as a luxury (1, 27). LMICs typically face issues regarding the allocation of limited resources, and high preventable mortality rates (27). In Malaysia, this is less of an issue – it is an upper-middle income country, but is nonetheless still regarded by the United Nations as ‘developing’ (28, 29). The prioritisation of other medical specialties and a focus on enhancing national infrastructures have been argued to prevent the government from committing significant resources to palliative care (4, 5, 7, 27). However, as Singer and Bowman (2002) argue, this must also be weighed against the neglect of quality end-of-life care, itself a significant humanitarian crisis (27).

The interviews extensively discussed a perceived lack of awareness of palliative care amongst local healthcare professionals and the wider Malaysian public. Respondents described miscon-

ceptions, such as notions of palliative care as ‘only for dying patients’, which they regarded as hindering its acceptance amongst patients and clinicians. Many respondents mentioned resistance from patients, their families, and clinicians in referring patients to palliative care, equating it to a “death sentence” and contributing to patients’ late referrals. This is ultimately detrimental to palliative care, resulting in poor patient outcomes which then reinforce its associations with death (3, 7). Namasivayam et al. (2013), Hamzah (2010), and Lim (2004) have all previously remarked on the poor awareness and acceptance of palliative care despite its establishment in Malaysia over 20 years ago (4, 5, 13). Such notions are not exclusively Malaysian, with poor understandings of palliative care still prevalent in other countries, especially where it is relatively nascent (1, 10, 30, 31).

More generally, respondents described a lack of prioritisation of palliative care, and its impact on their endeavours to further Malaysian palliative care. They cited the minimal funds received from the government and the lack of prioritisation of palliative care by policymakers. Palliative care has not been well-received by the wider medical field, which has affected the relationship between palliative care providers and those from other specialties (3-5, 7). The challenges experienced by local palliative care NGOs in establishing palliative care awareness and acceptance concur with ‘death-denying’ norms discussed in the wider social sciences literature (32, 33). Zimmermann and Rodin (2004) have argued that death-denying practices counter the principles of palliation: they discourage the acceptance of death, instead pushing for further curative interventions, despite their futility (33). The general resistance of clinicians towards palliative care can also be attributed to a form of “death-denying”, as their emphasis on curative treatments and the avoidance of death paint palliation as a “failure of medicine” (33, 34). Seale (2000) has described how similar entrenched attitudes and practices regarding palliative care were once evident amongst clinicians in the United States of America and UK, which provides some promise for Malaysian palliative care in that it demonstrates that such beliefs can be ameliorated to enable the advancement of the field (35).

Insufficient capacity and limited resources are not issues specific to Malaysia, with such matters affecting palliative care providers in LMICs as well as high-income nations, albeit to different extents (1, 10, 30, 31). In thinking about how services internationally might work within a financially straitened environment, we might glean some insight from how palliative care NGOs have shored up resources in challenging circumstances. In particular, the respondents in this study underscored the significance of advocacy work. This entailed, among other things, developing good working relationships with the media and putting on fundraising benefits. Such advocacy was understood to promote information about services, which was in turn regarded as augmenting the attention of policymakers, clinicians, and the wider public (including donors) to their work. By attracting attention and generating sponsorship that further enhanced the work of the NGOs (which then might attract further investment), the respondents contributed to developing a positive feedback loop that seeks to counteract the negative feedback loop of poor stereotypes resulting in late referrals.

Implications of research findings

The research findings provide updated information on NGOs’ role in Malaysian palliative care, emphasising their contributions to its development and advocacy. It spotlights the various barriers faced by NGOs in developing and providing palliative care. The arguments presented by respondents and the wider literature present numerous recommendations to advance palliative care.

These include the need for greater advocacy to increase awareness of palliative care amongst the public and wider medical field (3-5). This would help to negate the various misconceptions regarding palliative care, and increase its acceptance. To accomplish this, NGOs need to emphasise awareness campaigns that should also incorporate paediatric palliative care and palliation for non-cancer patients, as these have largely been neglected by mainstream palliative care (8, 17).

Furthermore, there is a need for specialised palliative care education in the local medical and nursing curriculum, which respondents proposed to mitigate the dire shortage in palliative care specialists in the country. This entails negotiating with the Ministry of Education to develop and integrate these courses. NGOs (and their donors) could also intensify their educational and research endeavours to support this, along with targeted fundraising, by conducting more seminars and workshops on palliative care, and through increased research into the field.

Wider co-operation between NGOs, the government, and the private sector is also necessary, to facilitate the sharing of resources and encouraging the national integration of palliative care. Similarly, there needs to be recognition that palliative care is not solely the responsibility of palliative care NGOs, but one that is shared amongst the other sectors (3, 5). The government is a major stakeholder, and should act to prioritise and commit further into the national advancement of palliative care.

Overall, this study generated findings concurrent with currently available literature, and furthers this knowledge by elucidating new perspectives on the subject. It also demonstrates the numerous endeavours of palliative care NGOs to advance Malaysian palliative care, and their progress thus far.

Study limitations

The demographic of respondents was heavily biased towards those of management staff – this was unavoidable since most of these NGOs did not have many healthcare staff due to their small-scale operations; this was further limited by the English proficiency required in the recruitment criteria. Despite these sampling limitations, a good range of respondents were interviewed, which reflects in the diversity of findings generated.

Although all respondents were fluent in English, it was not their first language in many cases. They were all able to sufficiently understand the nature of their involvement in the study and consent to their participation. Concerns relating to the extent of the respondents' English proficiency arose during the interview and data analysis process, with numerous instances of respondents requesting clarifications regarding the interview questions posed, and evidence of poor English language skills in several interviews. Therefore, we cannot discount the possibility that their responses to the interview questions, or their interpretation of the questions themselves, may be affected by this.

CONCLUSION

This study employed qualitative research methods to examine the current state of Malaysian palliative care. The interviews conducted identified numerous barriers hindering Malaysian palliative care, including financial and staffing concerns, logistical issues, government policies, and local perceptions of palliative care. NGOs negotiate these through fundraising, increased advocacy and research, and by forging strategic partnerships with other NGOs and sectors. Palliative care is making progress nationally, but there still exists areas for continued development. Existing services cannot meet the current demand, which is projected to rise (3). These challenges are not insurmountable, as evidenced by successful palliative care systems in other nations (1). Findings from this study present several recommendations to advance palliative care nationally, including the continued need for (perhaps, more explicitly targeted) advocacy through awareness campaigns, the establishment of specialised palliative care education, enhanced research efforts, and increased co-operation between the different sectors. Overall, the findings from this study help illuminate the current challenges Malaysian palliative care NGOs face, and provide recommendations to mitigate these.

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